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THE SOCIAL AND REHABILITATION
Record

Volume 1, Number 6 June 1974

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Social welfare group studies rural people

The Social Welfare Research Institute at the University of Denver has recently completed two projects on rural populations. They are summarized in two publications.

The Human Services in Rural America: An Assessment of Problems is a three-part project consisting of 1) an extensive review of the literature; 2) papers on demographic data and social trends, economic development, poverty and income maintenance, employment, transportation and communication, education, housing, health, family planning, mental health and mental retardation, nutrition, legal services, and social services; and 3) an annotated bibliography.

The Migrant Farm Worker: Social Programs, Policies, and Research includes demographic data and description of migrant life; information on the areas of employment, unionization, housing, education, health, income maintenance, and social and legal problems and services; and policy questions and considerations for the future.

Severely disabled in Alabama eligible for rehabilitation services

After the Alabama legislature appropriated $400,000 to the State Vocational Rehabilitation Service, the VRS now designates eligibility for comprehensive medical rehabilitation services to persons with spinal cord injuries or other serious physical handicaps.

With federal matching funds, this program will be allocated about $2 million for its first year's operational budget. The Research and Training Center at the University of Alabama will work with the VRS in implementing this program in the State.

A patient handbook on spinal cord injury has been developed by the R & T Center's rehabilitation nursing team as part of the total education in self-care for the catastrophically disabled. The manual describes and illustrates methods for performing procedures in the home utilizing equipment readily available to the patients and their families.

The handbook is used as a training aid with each patient during predischarge planning, and patients use it as a reminder of the proper steps necessary to live in optimum health despite their disabilities. The manual has been distributed to Alabama Public Health offices, Visiting Nurses Association, Vocational Rehabilitation Service, Crippled Children's Service, and various insurance companies.

Epilepsy employment ideas used by county

A program to improve the job placement of people with epilepsy has been undertaken by the Vocational Rehabilitation Center of Allegheny County, Pa.

What is new about the project is the education of the employer as well as the prospective worker. Employers will be able to see the job performance of someone with epilepsy before making a decision to hire.

Employers' on-the-job training expenses would be reimbursed at the rate of 75 percent the first month, 50 percent the second month, and 25 percent the third to help defray the cost of training new employees. The idea is to encourage hiring by making sure that businessmen do not incur extra costs. The rehabilitation agency also is lining up transitional jobs in the Pittsburgh area to show employers that applicants with epilepsy can compete in real work situations.

Changing attitudes is Chicago project aim

Access Chicago, an ongoing community project developed by the Research and Training Center, Northwestern University, aims to develop a greater awareness and understanding of the barriers that limit the accessibility of public facilities to the elderly and handicapped person; to explore the prospects of eliminating these barriers through technological, legal, financial, and organizational change; and to develop a blueprint for action to eliminate these barriers.

The project which began in 1972 has achieved significant results. Through its efforts, the Chicago City Building Code has been altered to require barrier-free construction of all new and major renovated public buildings.

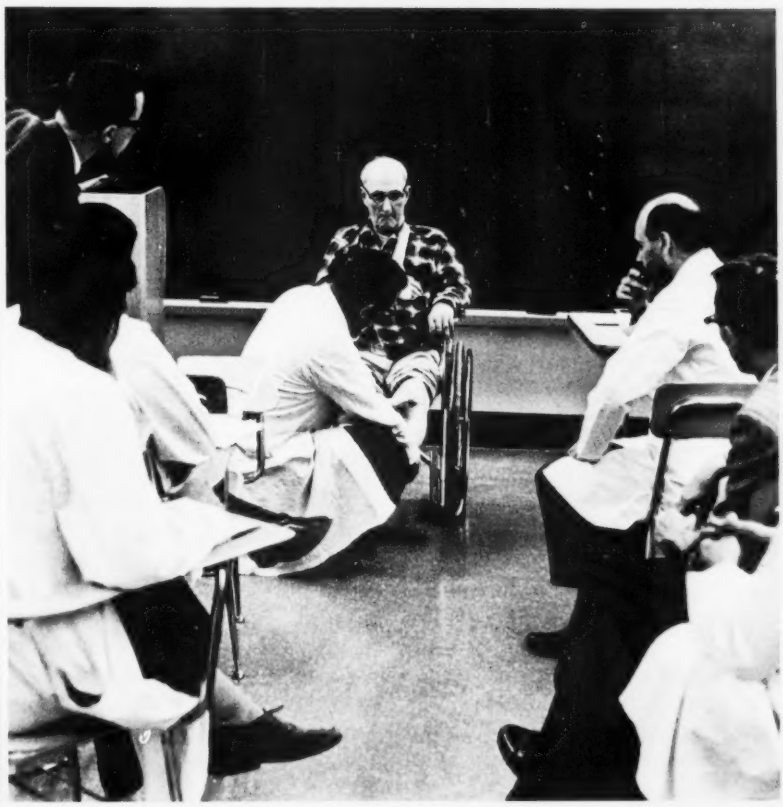
Working with the Illinois Governor's Committee on Employment of the Handicapped, the project has prompted an opinion by the State Attorney General that public schools are public buildings subject to the State statute requiring handicapped-accessible construction.

Access Chicago also is developing an extensive data base on transportation and architectural barriers, is implementing a public communication program which includes a speaker's bureau and consulting service, and is compiling a book, *Access Chicago—A Guide to the City.*

The project is demonstrating that the cooperation of the community in changing its attitude and behavior toward the mobility-limited and transportation and architectural barriers is gratifying, and, above all, possible.

Quality Health Care Primary Objective of Review Groups

THOMAS BRUBECK



While matters of management capture fewer headlines than such dramatic discoveries as Salk vaccine and open-heart surgery, the medical industry today is at the beginning of a quality assurance program which some predict will be one of the most significant changes since the adoption of Medicare and Medicaid 8 years ago.

Its name is Professional Standards Review Organizations (inevitably creating a new set of initials: PSRO), and its emphasis is on improving the quality of health care.

From a nationwide network of PSROs will come a system of health care surveillance. The object is to insure good care at a reasonable cost. The PSRO program will set standards for treatment, and local boards of physicians will review their colleagues' work for deviance from standards.

The PSROs will evaluate the necessity and quality of institutional medical care delivered under Medicare, Medicaid, and Maternal and Child Health programs. With a system of peer review, physicians will be examining the work of physicians. The review groups will be administered and controlled locally, not in Washington, D.C., or the State capitol.

The PSRO concept has not been without controversy and highly vocal opposition, but with Medicaid alone costing $12 billion a year (half of it federal money) a system of accountability was inevitable.

"There is no question," said the Senate report on why PSRO legislation was enacted, "that the govern-

ment has a responsibility to establish mechanisms capable of assuring effective utilization review. Its responsibility is to the millions of persons dependent upon Medicare and Medicaid, to the taxpayers who bear the burden of billions of dollars in annual program costs, and to the health care system."

The rapid rise in costs is due to the increasing unit prices and increasing number of services provided. Witnesses to the Senate Subcommittee on Medicare and Medicaid testified that a large proportion of health services provided are probably not medically necessary. The Senate report said, "Aside from the economic impact, the Committee is concerned about the effect of over-utilization on the health of the aged and the poor. Unnecessary hospitalization and unnecessary surgery are not consistent with proper health care."

Professional standards review, it was pointed out, will not only uncover unnecessary or superfluous services but also could turn up many instances of "under-utilization" or the absence of certain needed services.

The enactment of the PSRO program as part of the Social Security Amendments of 1972 (Section 249F, 86 Stat 1429) provides federal funds to encourage doctors to establish standards of care and to review the appropriateness and quality of the services. The new statute is to insure that payment for services under Medicare and Medicaid will be made only if services are 1) medically necessary, 2) meet professionally recognized standards of quality, and 3) are provided in the minimum duration and most economical level of institutional care appropriate to the patient's medical needs.

PSRO membership is open only to doctors of medicine and osteopathy.

The Department of Health, Education, and Welfare will pay for all expenses in carrying out the functions of PSROs, including payment to doctors for time spent in review.

Henry E. Simmons, Director of HEW's new Office of Professional Standards Review (OPSR), said the program will have an impact on 300,000 physicians, 170,000 other health professionals, 11 million hospital discharges, and 50 million people who are eligible for Medicare and Medicaid. Simmons' office is coordinating the PSRO activities of the National PSRO Council and related work in three agencies in HEW: the Social and Rehabilitation Service, Health Services Administration, and Social Security Administration.

Senator Wallace F. Bennett, who sponsored the legislation, said in an interview with *National Journal Reports* that he first became aware of the need for review of the quality of services given to Medicare and Medicaid patients when he read a Chicago newspaper article about how doctors teaching in medical schools were getting Medicare payments for work done on charity patients by interns and residents.

"We held hearings on that and came up with three possible solutions assuming a medical audit was needed," Senator Bennett said. "We could let the Social Security Administration build a series of audit offices; we could let private insurance companies do it, or we could let doctors check one another. The idea came from the AMA. They wanted to run it themselves."

The senator proposed the idea in 1970, but opposition from organized medicine killed the bill. It had better luck in 1972 when hospital costs were up to over $100 a day and people began to look at these costs more critically.

In March 1974, the HEW Secretary designated 203 geographic areas in which PSROs could be formed, and he invited physician groups to apply for contracts.

Thirty-one States will have statewide PSROs, and the remainder will have multiple areas. Each PSRO will include at least 300 physicians and is likely to have as many as 2,500.

The statute provides that in States where there are three or more physician review groups, the HEW Secretary will set up a Statewide Professional Standards Review Council to coordinate the activities of the several PSROs.

Only physician-sponsored organizations may be designated as PSROs until January 1, 1976. After that date, the HEW Secretary is authorized to contract with organizations with medical competence to function in areas where physician-sponsored groups could not be secured.

The review groups will come in many sizes and shapes. Howard N. Newman, Commissioner of SRS' Medical Services Administration,

said there is much flexibility, but there are certain essentials: 1) They must develop profiles for each patient, practitioner, and provider; 2) they have responsibility for determining whether various aspects of inhouse institutional review procedures are at levels of performance acceptable to the PSRO; 3) there must be broad and rotating physician participation in the review process—it is not a job for just a few doctors; 4) they must be organized on local bases of proper size; 5) the review groups must use acceptable norms as checkpoints in their review of care; and 6) data must be maintained in a way to facilitate evaluation of PSRO performance—in other words, to evaluate the evaluators.

The PSRO legislation was designed from the ground up, not from the top down. The review system is being built upon the practitioners of medicine and not its centrally organized bureaucracy, because PSROs are involved with on-the-spot medical practice.

Mr. Newman gives several reasons for his belief that the prognosis for PSROs is good: They involve physicians, and many physicians appear to be interested; they will be responsible for Medicare and Medicaid, and joint coverage will someday permit PSROs to incorporate utilization-review activities of health insurance companies; the PSRO system will be capable of covering more than institutional services; and management information systems, including computerized claims processing, will lend support in a program which will involve thousands of claims.

The government requires States to be responsible for utilization review of all services provided by Medicaid, while PSROs will initially be responsible for the review of institutional services alone. Unless States review the whole array of services and review them in every part of the State, they could be out of compliance with regulations and possibly lose federal funds.

"Even when States no longer have to worry about utilization review functions," said Mr. Newman, "they will have an interest in the success of PSRO, because from 17 to 50 percent of the funds spent on Medicaid in every State come from State or local treasuries."

Each PSRO will develop its own regional criteria, standards, and norms of care, usually related to age and diagnosis, and the author of the legislation states that these would be used as "checkpoints for quality" rather than barriers to care. The members of each PSRO will have the sole power to determine the acceptability of the criteria applicable in their area.

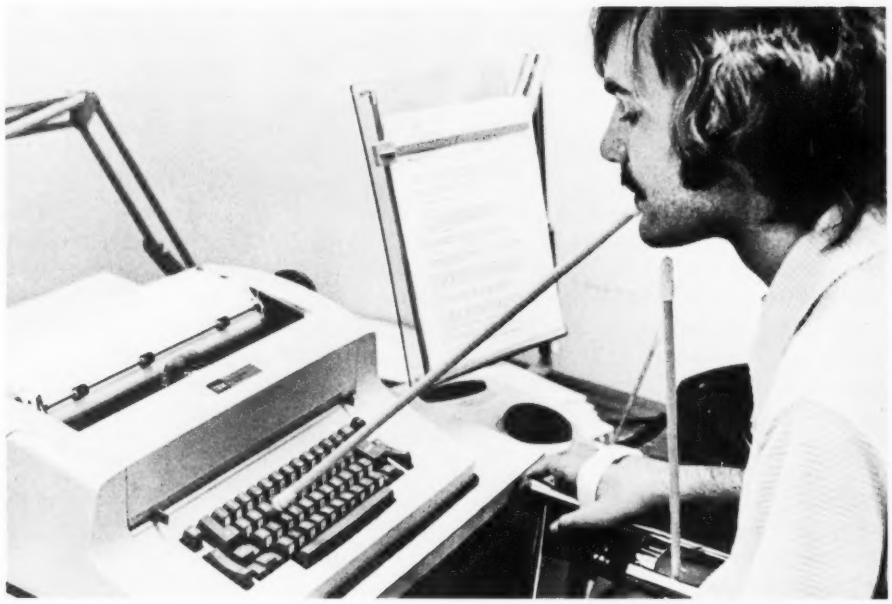
These indexes of medical necessity and quality would be used to indicate the points at which it would be reasonable for the reviewing physicians to ask an attending physician to indicate why he thinks additional hospitalization or services were required, or why certain services were not provided. To be most effective, institutional care review would be concurrent, not *ex post facto*, so that agreed-upon changes could prevent any unnecessary care. Thus, the objectives of the program are to be achieved primarily through educational means.

The program was not designed to be punitive, except in cases of blatant neglect or outright fraud. The most severe sanction that could be imposed upon physicians and "providers" (hospitals and other institutions) is disqualification from Medicare and Medicaid programs. A proposed hospital admission that is disapproved by the PSRO in advance will not be payable under Medicaid. The doctor can still admit the patient, but he, the patient, and the hospital would have to look beyond Medicaid for payment. This is similar to the practice of private health insurance with one improvement: Instead of care being provided and then having payment denied, everyone will know where he stands in advance rather than after the fact.

For the individual doctor, occasional service with the local PSRO will give him more exposure to the health norms and guidelines as well as an overview of the way health care is practiced in the community. Both as a practitioner and in the role of reviewer, his contact with the review group could help him professionally.

To the public—the taxpayers and millions of Medicaid recipients—good care at a reasonable cost is the obvious goal.

Mr. Brubeck is a contributing editor to *The Social And Rehabilitation Record.*



Rehabilitation Act Stresses Services to the Most Severely Handicapped

LOUIS NAU, PH.D., and JAMES S. JEFFERS

"A rose is a rose, is a rose. . . . " This logic may hold for flowers, but it does not hold for handicapped people. Any disability and its handicapping effect on life and employment are severe to the individual involved. Within the delivery systems which serve handicapped people, the degree of severity is directly related to the scope, complexity, extent, and costs of services for successful rehabilitation.

What kind of services are needed to vocationally rehabilitate a white, mid-20-year-old, suburban-dwelling, single male who has experienced a below-knee amputation? Or what services are needed to vocationally rehabilitate a black, late-40-year-old, rural-dwelling, divorced mother with four young children, who has become a paraplegic as a result of polio?

Past vocational rehabilitation legislation authorized services for both persons on an equal basis. In 1972, statistics show that of the 325,000 persons rehabilitated through the State-Federal vocational rehabilitation program, approximately 23 percent were classified as severely handicapped.

The Rehabilitation Act of 1973 (P.L. 93-112) mandates emphasis on "serving first those individuals with the most severe handicaps." The history behind this thrust was described by Kathaleen Arneson in "The Rehabilitation Act of 1973," *The Social and Rehabilitation Record*, December-January, 1973-74. However, to truly understand the impact of this mandate relating to its implementation, a review of the statutory language is important. Section 7, paragraph 12, states:

"The term 'severe handicap' means the disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, systic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe."

Why was such a straightforward and specific definition of "severe handicap" necessary? To answer one must review VR history.

Since its beginning more than 50 vocational years ago, the State-Federal vocational rehabilitation program has provided services to the severely handicapped. However, throughout the years, the severely handicapped were not being served proportionately to less severely handicapped persons. A myriad of reasons exists for this situation. Some concern the realities of administering a public social service program. Others concern the operating philosophy of the rehabilitation community resulting from the political arena in which it must function.

In developing and administering any public programs, accountability of expenditures becomes an inherent necessity. In our system of government where various interests compete for finite sums of public dollars, it is imperative that those interests demonstrate to the appropriating authorities (legislative bodies) that the expenditure of public funds promotes the common good and is consistent with the established public policy. Since these are rather broad and general parameters, the stage is set for stiff competition for the limited available resources.

The vocational rehabilitation program has fared quite well in this competition. State and federal administrators have succeeded in gaining support and endorsement from legislatures in appropriating significant amounts of money for the continuation and growth of the rehabilitation effort.

To do this, however, it has become necessary to quantify programs in terms of "*numbers* rehabilitated," resulting in the forced meeting and exceeding of annual quotas. Consequently quick or easy rehabilitations became important, while the severely handicapped, who require more time, effort, and dollars were served on a much more restrictive basis.

The reality of this approach constitutes an operating policy in which emphasis is placed on serving the less severely handicapped, who are most likely to benefit and attain successful rehabilitation with less investment of time, effort, and money than the "more" or "most" severely handicapped. That is to say, there is perhaps more economy in directing our rehabilitation efforts toward individuals who require less cost in terms of manpower and resources, and more benefits in terms of rehabilitations, when the outcome is measured by the sole criterion of "gainful employment."

The new direction for serving the severely handicapped contained in P.L. 93-112 minimizes the need for such an operating policy by placing greater emphasis on individualized and quality rehabilitations. It seeks to lessen the necessity to "play the numbers game" in order to maintain a progressive and responsive rehabilitation program.

Who, then, are the severely handicapped? The listing of disabling conditions provides general guidance only. In addition, the Rehabilitation Services Administration is providing specific guidance to State vocational rehabilitation agencies in identifying severe handicaps through a criterion

of functional limitations and through other factors.

The severely handicapped have a disabling condition or multiple disabilities so severe and complex that they require a number of rehabilitation services, delivered over an extended period. For example, the quadriplegic described previously would require multiple services over a long period. On the other hand, a person having a marginal hearing loss may not be severely handicapped if the disabling condition can be corrected by simply providing a hearing aid.

Severely handicapped people are not found in any one place nor do they all require just one kind of service. Many are homebound, receiving no specialized rehabilitation services at all. Some are receiving custodial care in nursing or convalescent homes. Others are receiving physical restoration in hospitals and other medical facilities. A number are receiving a broad variety of physical medicine and rehabilitative services in comprehensive rehabilitation centers. A significant number are engaged in sheltered employment in rehabilitation workshops. A few have been rehabilitated to the extent that they are actively employed in the competitive labor market.

It is the goal of the current rehabilitation effort to offer the severely handicapped the kinds of rehabilitation services which will lead to increased opportunities for competitive employment.

The job of their rehabilitation involves much more, however, than the treatment of the physical or mental handicapping conditions. There are more elusive and highly complex subjective aspects which frequently complicate the rehabilitation process. There are many sociological and psychological factors which can only be dealt with in a comprehensive manner in a person's rehabilitation program.

The severely handicapped person must face such obstacles in the rehabilitation process. Being able to deal with the ancillary effects of being different from the rest of society is a major task. Contemporary thinking, as characterized by this public pronouncement: "In the 'Pepsi generation' where everyone is beautiful and no one passes the age of 28, no place remains for the lame, the halt, and the blind," constitutes a barrier to rehabilitation which frequently may be more insurmountable than the physical or mental condition itself.

From within, the severely handicapped must cope with psychological barriers of his own creation. A young energetic person who, in a moment, finds himself a traumatic paraplegic must grapple with the stark reality of being forced to alter and adapt suddenly and reluctantly to a unique and alien mode of living.

A statement in the August 15, 1971, issue of the Chicago Tribune Magazine article, "Who Cares for the Broken Man," aptly describes the plight of many severely handicapped persons: "Through the accident of a moment, they have become lifetime members of a special minority; an aberrant class feared or despised or patronized by the ambulatory majority."

From outside himself the person must deal with the predispositions, the sterotyping, the fears, and the rejections of the general public. At the same time he must cope with both the physiological and the phychological changes brought about by the disabling condition.

But there is help for the severely handicapped. It is available from friends, relatives, and a variety of concerned persons who are skilled in the area of physical medicine and rehabilitation.

The vocational rehabilitation legislation has offered a formal service delivery approach which is responsive to the unique needs of this group. There is no one method, no one service, no one plan which can meet the needs of all of them. For this reason, an individually-designed and jointly-planned rehabilitation program is provided for each client. It takes into account as many of the variables, needs, and realities as possible. Through this process, the client embarks upon a service process with successful rehabilitation as its goal.

In 1959, Henry Viscardi, Jr., a very successfully rehabilitated severely handicapped man, published a provocative and challenging book, *Give Us The Tools.* In it, he vividly described severely handicapped persons, their needs, their rehabilitation program, and the services which contributed to a successful rehabilitation. Since its publication, some things have changed. Physical restoration and surgical techniques have been greatly advanced. Prosthetic and orthotic devices have benefitted extensively from technological research and development. Rehabilitation service facilities have increased in number and scope, far beyond the expectations of 1959.

With the future thrust of rehabilitation aimed specifically at serving the severely handicapped, all the service expertise of vocational rehabilitation and physical medicine must be employed to that end. Vocational rehabilitation agencies have provided an array of services to successfully rehabilitate over 2 million people. These services include evaluation, vocational training, counseling, maintenance, physical restoration, job development and placement, followup, and other supportive services.

The array of services for the severely handicapped is not different. They are, however, more intensive, more versatile, more technologically adapted to the needs of the client, more professionally supervised, and, yet, still personally, empathetically, and humanistically administered. Special programs are being developed for the low-achieving deaf, the older blind, and people needing kidney dialysis.

For example, the Center for Independent Living in Berkeley, California, together with the Physically Disabled Students Program (PDSP) of the University of California at Berkeley has established a service system to provide for care for homebound and immobile handicapped persons, a wheelchair maintenance and repair service, and an active legislative development program with the Berkeley City Council which is making possible the systematic elimination of "all" architectural and physical barriers along the streets and sidewalks of the growing city.

A system of comprehensive spinal cord injury centers has been estab-

lished in many cities around the country. The centers provide for immediate, onsite air evacuation of traumatic spinal cord injured patients to facilities especially staffed, equipped, and designed to offer maximum service.

Great scientific breakthroughs may be near as a result of current research in spinal cord injury. Using a saline solution at 5 degrees centigrade as a wash, initiated within the first 2 hours after injury and lasting for an extended period of time, or the injection of corticosteriod within the first 4 hours after injury, and other such innovative procedures encouraging results have been provided in reversing the otherwise irreversible effects of spinal cord injury.

There are a number of comprehensive model rehabilitation centers which are developing and perfecting rehabilitation service systems to meet the total needs, not only of the handicapped person, but also the resultant and residual rehabilitation needs of other family members.

A Comprehensive Needs Study, now being conducted by the Rehabilitation Services Administration, is determining the feasibility of methods to meet both the vocational and quality of life needs of the most severe handicapped, those who, heretofore, have been judged ineligible for such services.

Through such services and many more, an ever increasing number of severely handicapped persons is receiving much needed assistance. Through the findings of current research, through the technological advances now anticipated, and through the training development of more skilled rehabilitation personnel, increased numbers of handicapped persons will benefit from additional opportunities for more complete rehabilitation.

There are currently millions of severely handicapped persons in the U.S. In the next several years, there will be millions more born with or who will suffer severe disabilities. Recognizing this fact, we as a society have made a commitment of manpower and resources to provide to them the most comprehensive rehabilitation humanly possible. We have initiated an extensive research program to address the phenomenon of disability and to develop the technological and medical expertise necessary to provide rehabilitation processes fully responsive to the needs of the handicapped.

Commitment of manpower and resources, however, is not enough. The rehabilitation of the severely handicapped requires the establishment of a delivery system uniquely designed to meet individual needs. Rehabilitation, as a process, must approach individual needs in their totality.

We must remember that the rehabilitation effort cannot function in a vacuum. It must deal with the individual's needs as they relate to other societal and familial relationships.

In this regard, the successful rehabilitation of the severely handicapped will challenge the basic ability of the society to undergo one of the most difficult and significant processes known to mankind: a process of attitudinal change. We must, as a social unit, learn to appreciate and respect the handicapped as individuals, who have the same basic wants, desires, and needs as other persons. We must be willing to extend our commitment to offering them the same opportunities for housing, transportation, recreation, and employment as we do other people.

That challenge, and how we address it, will truly be the test of our commitment for successfully serving and rehabilitating the severely handicapped.

Dr. Nau is Executive Assistant to the Commissioner, RSA, and Mr. Jeffers is Legislative Assistant to the Administrator, SRS.

TAKE TEN!

Ten television programs on alcoholism—how men and women are rehabilitated.

The half-hour programs on this major killer, produced by the National Broadcasting Company in cooperation with SRS, are being shown in Washington, Cleveland, New York, Los Angeles, and Chicago through August. Check local stations for time. This fall, the telecasts also will be offered to 200 NBC affiliates. The series will be available later for public service use on 16mm color film. Order from the National Audio-Visual Center, Department of Archives, Washington, D.C. 20409.

1- Alcohol and its Past
2- Alcohol and Myths and Money
3- Alcohol and the Man
4- Alcohol and the Woman
5- Alcohol and the Teenager
6- Alcohol and the Clinic
7- Alcohol and Therapy
8- Alcohol and the Family
9- Alcohol and Accidents and Crime
10- Alcohol and Insight

Child Abuse and Neglect Concerns SRS Multi-Efforts

GERALDINE E. McKINNEY and
GAROLD D. RAFF, JR.

The Social and Rehabilitation Service (SRS) has six objectives involving $400,000, as a part of its contribution to the Child Abuse and Neglect Intradepartmental Committee appointed by Secretary Weinberger. In addition, SRS has contributed $500,000 for joint demonstration projects.

The six SRS objectives include a reconnaissance of information from State and local welfare departments, research on early warning signals, development of a system to evaluate effectiveness of abuse and neglect services, development of service guides, a "state of the art" study on child neglect, and use of Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) to identify abuse and neglect in early stages.

The demonstration projects are directed toward new and innovative approaches, particularly as they relate to integrated and coordinated delivery of communitywide services to abused and neglected children and their families.

Overall Intradepartmental Effort

The protection of children is largely a State and local responsibility, carried out through a variety of statutory provisions, including criminal law, juvenile court acts, protective services legislation, and child abuse and neglect reporting laws. Federal moneys are available under title IV-A and B of the Social Security Act, largely on a matching basis with State and local expenditures.

The DHEW Intradepartmental Committee was appointed to identify federal efforts which would help State and local agencies find better approaches for dealing with child abuse and neglect. The Secretary directed the Office of Human Development (HD), through the Office of Child Development (OCD), to take the lead in examining the problem and to develop a departmental plan to coordinate action. The agencies involved are the Office of Child Development, Social and Rehabilitation Service, Office of Education, Office of Public Affairs, and the health agencies of the Department.

Secretary Weinberger further instructed DHEW agencies to earmark $4 million of research and demonstration funds in Fiscal Year 1974 for new activities focused on the problem of child abuse and neglect. The $900,000, plus staff resources identified above, is SRS' contribution to this overall effort. In addition to participation in the work of the Intradepartmental Committee, SRS has designated training in child abuse and neglect services as one of the national priorities within the 1974 child welfare training program.

Specific SRS Activity

As a part of our support for the Secretary's Committee efforts, SRS has consistently provided advice and guidance and directed the following:

■ *Child Abuse and Neglect Services Demonstration Project.* SRS has contributed $500,000, along with $900,000 from the Office of Child Development, to fund 11 demonstration projects in eight regions. The money will be used to develop new and innovative approaches aimed at public awareness of the problem; educate the public in the detection, prevention, protection, and care of the abused or neglected child and his family; identify behavior patterns that suggest the potential for abuse or neglect; and help develop an integrated and coordinated approach to the delivery of essential services to children and their parents or caretakers. The demonstration projects are anticipated to be funded for 3 years.

■ *Reconnaissance of Selected State and local Welfare Departments on Abuse and Neglect Services.* A survey was conducted in 10 State and 30 local welfare departments in November and December 1973. This study asked for information on major problems in providing services to abused and neglected children and their families, legal requirements and processes, program administration, program description, community support, and the Department's view of the federal role.

The information secured in the survey of services will have several uses. At the federal level it will help in looking at program administration, in determining the major problems departments of social services, State and local, are facing in the provision of these services, and will be helpful in the development of guides for service delivery systems. It will also provide useful information to the Regional Offices in work with the States.

■ *Research Project on Early Warning Signals of Child Abuse and Ne-*

glect. Because much abuse and neglect can be prevented or reduced by early detection and services, a 3-year research project is looking into early warning signals which indicate a need for intervention. The project also will test the effectiveness of appropriate services to families identified by early warning signals.

■ *"State of the Art" Study on Child Neglect.* A second research project has been funded to produce a "State of the Art" study on child neglect which will analyze and synthesize research and demonstration findings and the experience of experts. This will supplement the Office of Child Development's "State of the Art" study on child abuse.

■ *Evaluation System for Measuring Cost-Effectiveness of Protective Services.* Program analysis of protective services will be used to develop an evaluation system to measure the results of protective services. As a part of the analysis, a review will be made of the survey, which was recently completed in 10 States and 30 local departments of social services. Preliminary results indicate that agencies want and need to develop better methods of evaluation in order to plan and provide appropriate services more effectively. The evaluation system developed in this project will be tested in various sites and transmitted to State and local governments for their use.

■ *Use of Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) to Recognize and Treat Child Abuse and Neglect.* The EPSDT program will be utilized to recognize and treat child abuse and neglect in various ways. One will be the development, in collaboration with the American Academy of Pediatrics, of material to be used in a manual of guidelines for use in EPSDT.

■ *Guides for Model Delivery Systems.* As the final project, SRS plans to develop guides to assist State and local social service agencies to improve their administration and delivery of services, based on some indepth analyses of exemplary local programs.

Other HEW Agency Activities

Other agency activities within HEW interrelate with those of SRS. The more prominent of the agency efforts are summarized below.

Office of Child Development (OCD). In addition to OCD's efforts on the 11 demonstration projects, OCD will develop and utilize a survey instrument to review local public and voluntary child protective service programs. This should lead to developing program models for demonstration in fiscal year 1975; testing the feasibility of a national clearinghouse; awarding a grant to establish and determine the effectiveness of self-help groups; providing informational materials and support to Head Start programs and experimental projects to include an emphasis on identification; and awarding a grant for the revision of the model Child Abuse and Neglect Reporting Law.

The Office of Education is developing a model for training teachers to identify abused and neglected children, work with other community resources to alleviate the problem, and develop the skills necessary to aid abused and neglected children overcome emotional trauma.

The Office of Public Affairs is providing public service materials to inform and educate the American public about the Department's priority efforts.

The Health Agencies of the Department are involved in the following subobjectives: developing, publishing, and issuing guidelines to 1,500 Bureau of Child Health Services-funded projects and their affiliated backup hospitals for organizing the identification and management of child abuse and neglect in existing health service delivery settings; funding various research projects concerned with the biomedical and mental health aspects of child abuse and neglect; taking the lead in evaluating, jointly with SRS and OCD, the effectiveness of the multidisciplinary demonstration projects; funding research projects that are related to various existing systems of health care delivery and management of child abuse cases in health settings and, through cooperative arrangements with other agencies, testing various mixes of services and the effectiveness of such services.

This Intradepartmental Committee effort has been one of the more successful examples of HEW agencies working together to accomplish a coordinated set of objectives. SRS' commitment to making this effort work has been substantial. SRS continues to work through the Committee to encourage State and local agencies to better overcome circumstances leading to the abuse and neglect of children.

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SRS–Health Join Forces on Family Planning for Poor

LOWELL B. GENEBACH, JR.

Americans generally accept the idea that all persons should have the opportunity to plan the size of their family and that the government should assist low income people to have the same access to modern, effective means of controlling family size as people with higher income. In recent years, federal policy expressed in law and regulation has made it possible for Aid to Families with Dependent Children (AFDC) and Medicaid recipients to obtain a broad range of family planning services when requested.

This article describes current SRS policies for family planning services under the AFDC and Medicaid programs, our efforts to coordinate our goals with the Public Health Service, SRS evaluation project plans, and administrative goals.

AFDC

The Social Security Amendments of 1967 made mandatory the provision of family planning services under AFDC. The 1972 amendments broadened and strengthened the program. Under current law, States must offer and provide promptly, directly or under arrangements with others, family planning services to all appropriate recipients of AFDC (including minors who can be considered sexually active) who desire such services.

Further, they must offer and provide these services when requested, to appropriate persons who have been applicants or former recipients of AFDC if the State plan includes family planning services for these groups. In addition, the law imposes a penalty of 1 percent per year of the federal share of total AFDC Title IV-A funds on any State which, in the preceding year, failed to offer these services to appropriate people and to provide such services to those freely desiring them.

Medicaid

Under current law, the provision of family planning services is also mandatory under Title XIX, although there is no comparable penalty to be applied against the State's Title XIX program for failing to provide them.

The cost of family planning services is reimbursable at 90 percent federal matching under both programs. The 90 percent federal matching available under both programs serves as an inducement for program improvement and, the penalty provision under AFDC provides added incentive toward that end.

Services Defined

Under AFDC, the following family planning services are matchable with federal funds: social, educational, and medical services to enable appropriate persons (including minors who can be considered to be sexually active) voluntarily to limit family size or space children and to prevent or reduce the incidence of births out of wedlock. Such services include printed materials, group discussions, and

TABLE 1 DHEW Programs for Delivery of Family Planning Services

Function	Local Delivery Agency	DHEW Operating Agency with Funding and Program Responsibility
Medical Services (either as separately organized services or integrated into larger systems of maternal or comprehensive care), Information, Counseling, and Referral	Hospitals and Clinic Services	**HSA**[1] —Indian Health Service —Federal Health Programs Service —Bureau of Community Health Services **ADAMHA**[2] —National Institute of Mental Health **SRS**[3] —Medical Services Administration —Community Services Administration
	Health Departments	**HSA** —Indian Health Service —Federal Health Programs Service —Bureau of Community Health Services **SRS** —Medical Services Administration —Community Services Administration
	Voluntary Health Agencies	**HSA** —Indian Health Service —Federal Health Programs Service —Bureau of Community Health Services **SRS** —Medical Services Administration —Community Services Administration
Medical Services (either as separately organized services or integrated into larger systems of maternal or comprehensive care), Information, Counseling, and Referral	Private Physicians	**SRS** —Medical Services Administration —Community Services Administration
Information, Counseling, and Referral only	Public Assistance Agencies	**SRS** —Community Services Administration —Medical Services Administration —Assistance Payments Administration
	Voluntary Social Agencies	**SRS** —Community Services Administration —Medical Services Administration —Assistance Payments Administration
	Employee Health Services	**HSA** —Bureau of Community Health Services —Federal Health Programs Service

1. Health Services Administration
2. Alcohol, Drug Abuse and Mental Health Administration
3. Social and Rehabilitation Service

individual interviews which provide information about and discussion of family planning, medical contraceptive services and supplies, and help in utilizing medical and educational resources available in the community.

Under Medicaid, federal matching for family planning includes: Payments for necessary medical examinations, diagnosis, medical counseling and treatment, laboratory services, surgical procedures, drugs, supplies, and devices. These services may be provided in doctors' offices, clinics, hospitals (on both an inpatient and outpatient basis), and in family planning centers or any suitable setting.

See Table 1 for a summary of Department of Health, Education, and Welfare family planning programs for delivery of services by function, local delivery agency, and DHEW operating agency with funding and program responsibility.

Requirements to Avoid Penalty

To avoid the 1 percent penalty, States must assure that the following requirements are accomplished:

- That each appropriate person is offered family planning services (with parental consent when it is legally required);
- That the offer is made within 31 days of the first assistance check and once a year thereafter;
- That acceptance of family planning services is voluntary;
- That services are initiated or arranged for as soon as possible after being requested and, in every case, not later than 30 days after the request; and, in conclusion,
- That effective April 1, 1974, the States establish and maintain documentation of the offering, request for, and prompt provision of family planning services to substantiate federal financial participation claimed for these services and to meet minimum SRS statistical reporting requirements.

State agencies must provide the needed services, as requested, and as covered in their State plan, either directly by the Title IV-A agency staff or under arrangements with others; *i.e.*, purchase of such services under either Titles IV-A or XIX, or referral to some other resource, such as maternal and child health or family planning projects.

Program Coordination

Family planning services are a Departmental concern. In view of the significant responsibility which SRS has in assuring that AFDC and Medicaid resources are made available to the maximum extent possible and the responsibility which Public Health Service has for providing the medical expertise required, both organizations are working closely together.

SRS and the Public Health Service are assisting all projects in obtaining recognition as being eligible for reimbursement by Medicaid and AFDC. Both are working with the States to identify gaps in services coverage and to develop and implement mechanisms for filling these gaps.

Through joint SRS/Public Health Service coordination efforts, we believe that our regulations, guidelines, and other family planning service policy statements reflect the interests and responsibilities of each; our technical assistance plans will provide State agencies with the full range of assistance needed in the medical, social, and financial areas; and our data gathering systems are being designed to facilitate the collection of family planning information needed by both organizations.

Evaluation Project

The rapid growth of federal family planning programs raises questions about their effectiveness and overall impact on the very goal of preventing unwanted births. One central, overriding question is: How effective are family planning services in achieving what they set out to accomplish? This question is particularly important to SRS which in coming years will be providing a significant proportion of DHEW financing under Titles IV-A and XIX. Hence, in the months ahead, SRS will make Federal-State impact evaluation studies of family planning programs under both Titles.

These studies will provide information on the impact of social services on utilization of family planning resources, and the impact of family planning (social and medical) services in reduction of unwanted births, births out of wedlock, and spacing of children. In addition, they will provide data regarding recipient characteristics in relation to programs.

The information obtained will be useful for policymakers in assessing the importance and value of social services in the provision of family

TABLE 2 Family Planning Estimates

	ESTIMATED FEDERAL EXPENDITURES (In Thousands)				ESTIMATED NUMBER OF RECIPIENTS (In Thousands)				ESTIMATED FEDERAL COST PER RECIPIENT			
	FY '72	FY '73	FY '74	FY '75	FY '72	FY '73	FY '74	FY '75	FY '72	FY '73	FY '74	FY '75
Title IV-A (AFDC)	25,900	49,657	52,705	60,610	1,000	1,602	2,774	3,367	$24.00	$31.00	$19.00	$18.00
Title XIX (Medicaid)	8,700	18,200	30,600	36,000	350	450	700	780	$25.00	$41.00	$44.00	$46.00

planning services. Finally, it will assist States in choosing the most cost-effective service for inclusion in their programs.

Administrative Goals

The major SRS administrative goals during the remainder of FY 74 and FY 75 in the area of family planning include for both the AFDC and Medicaid programs providing State agencies needed medical, social, financial, and data systems gathering technical assistance; and reviewing the family planning systems in each of the 50 States, D.C., Guam, Virgin Islands, and Puerto Rico and assessing penalties against those failing to comply with the Social Security Act, Title IV-A family planning penalty regulations, standards, and procedures.

This is necessary to insure that all 54 "State" jurisdictions have a system in place that documents their family planning service programs and that allows objective, equitable assessment of penalties against the AFDC program when program requirements are not met.

Table 2 shows the dramatic rise in estimated federal expenditures and numbers served for family planning under AFDC and Medicaid since enactment of the Social Security Act amendments of 1972.

The decrease in AFDC cost and the corresponding rise in Medicaid cost per recipient results from a shift in the provision of medical services from the former to the latter in several key States. Such a transfer from a closed to an open end appropriation permits States to utilize AFDC services moneys in other critical areas.

The increased availability of family planning services through AFDC and Medicaid for those unable to obtain them at their own expenses should have a significant impact on efforts to alleviate or ameliorate dependency among the less fortunate in our society. Progress toward the ultimate goal of "every child a wanted child" should be measurably enhanced by bringing to bear these two formula grant programs.

Mr. Genebach is Acting Assistant Administrator for Operational Planning and Control, SRS.

The Administrative File

Each month the SOCIAL AND REHABILITATION RECORD will carry a listing of SRS administrative issuances for previous months. Over the course of a year, the RECORD will have presented a complete bibliography of administrative issuances for the year.

The following are the administrative issuances for the month of March 1974. (Abbreviations key: **PR**-Program Regulations; **PRG**-Program Regulations Guides; **PI**-Program Instructions; **IM**-Information Memoranda; **FSI**-Field Staff Information and Instruction Series; **AO**-Administrator's Office; **MSA**-Medical Services Administration; **APA**-Assistance Payments Administration; **CSA**-Community Services Administration; **RSA**-Rehabilitation Services Administration; **NCSS**-National Center for Social Statistics.)

When ordering reports, please specify the appropriate room number for the particular report: For NCSS reports, write NCSS Reports Clerk, Room 2620; for PR reports, write PR Reports Clerk, Room G-115B; for AO reports, write AO Reports Clerk, Room G-115B; and for all other reports, write Reports Clerk, Room 5219.

Send all requests with the appropriate room number to Social and Rehabilitation Service, U.S. Department of Health, Education, and Welfare, 330 C Street S.W., Washington, D.C. 20201.

CSA-PI-74-8: Interim State Plan for Services Under Title VI of the Social Security Act (3/1/74)

CSA-PI-74-10: Interim State Plan for Services Under Title VI of the Social Security Act—Services to Former and Potential Applicants and Recipients (3/21/74)

NCSS-IM-74-6: Summary Listing of Forms to be Submitted to the National Center for Social Statistics (3/11/74)

NCSS-PI-74-21: Supplementary Instructions for the State Agency Program Expenditure Projection Report (SRS-OA-25) (3/25/74)

AO-PR-70-1 (C-3): Correction to Interim VR regs (3/1/74)

AO-PR-40-14 (C-2): Regulations on Fraud in the Medical Assistance Program (3/1/74)

AO-PR-10-9 (C-2): Scope and Applicability of Title I, X, XVI of SSA (3/5/74)

AO-PR-10-16 (C-19); 40-7 (C-1); 10-11 (C-20); 40-27; 40-28; 40-29; 40-30-34: Medicaid Eligibility SSI (3/11/74)

AO-IM-74-34: Fee Schedules (3/7/74)

AO-PR-10-15 (C-2): Second Deferral of Effective Date of Sterilization Regs to 3/18/74 (3/8/74)

AO-IM-74-34: 4th Annual SRS Public Affairs Conference for State and Local Staff Members with Public Information (3/8/74)

AO-PR-10-15 (C-3): Third Deferral of Sterilization (3/22/74)

AO-IM-74-36: Correction to Medicaid Eligibility (3/20/74)

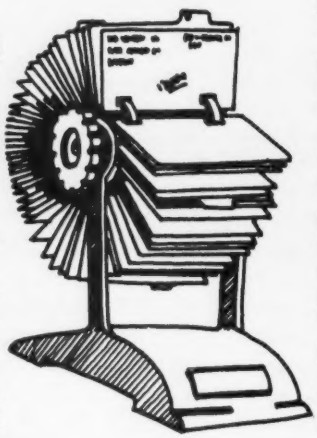
RSA-IM-74-45: Principles Basic to the Establishment and Operation of Postsecondary Education for Deaf Students (3/22/74)

RSA-IM-74-46: "Vocational Rehabilitation for the Blind and Disabled" (3/25/74)

RSA-IM-74-47: Distribution of the "Quarterly Status Report of Social Security Disability Insurance Beneficiaries—Quarter Ending December 31, 1973" (3/28/74)

RSA-PI-74-23: Basic Assumptions and Guidelines for Completion of Program and Financial Plan for State Vocational Rehabilitation Agencies for FYs 1975, 1976, and 1980 (3/11/74)

RSA-PI-74-24: OMB Approval of Revised Statistical Forms SRS-RSA-100, SRS-RSA-101, And New Form SRS-RSA-102.



RSA-PI-74-25: Deletion of Names and Addresses from the Individual Case Service Report, Form SRS-RSA-300 (3/22/74)

RSA-PI-74-26: Form SSA-853 (Revised 1-74), Vocational Rehabilitation Report to SSA (3/22/74)

RSA-PI-74-27: Verification of Eligibility for Supplemental Security Income Payments (3/25/74)

RSA-PI-74-28: *RIDAC* GUIDELINES (3/25/74)

MSA-IM-74-12: Increase in SMI Premium Rate Effective July 1974 (3/27/74)

MSA-PI-74-8: State Plan Amendment & Implementing Procedures for Final Regulations on Fraud in the Title XIX Program (SRS Program Regulation 40-14 (C-2), 45 CFR 250.80, March 1, 1974) (3/1/74)

MSA-PI-74-9: Skilled Nursing Facility and Intermediate Care Facility Regulations: *CORRECTIONS*

MSA-PI-74-10: Medicaid Eligibility Regulations—*CORRECTION*. In the Medicaid eligibility regulations published 3/11/74, the provisions on disability (Sec. 248.80) were incomplete.

MSA-PIM-74-11: Institutionalized Title XIX Patients—Personal Needs Allowance and Application of Excess Income to Cost of Care (3/15/74)

MSA-PIM-74-12: Federal Financial Participation for Buy-In Premiums for Persons Whose Eligibility is Extended Pursuant to Section 1902(e) (3/29/74)

MSA-FSI-74-50: Discontinuation of Reporting Required Under FSIIS-124, Mental Health (3/4/74)

MSA-FSI-74-51: Early and Periodic Screening, Diagnosis and Treatment-Program Implementation Report (3/8/74)

MSA-FSI-74-52: Updating Chart—"Medicaid Services State by State" (3/14/74)

APA-PI-74-10: Request for Information on Successful State Projects (3/5/74)

APA-PI-74-11: Record Retention and Custodial Requirements (3/8/74)

APA-IM-74-8: List of APA Program Issuances—November 1, 1973, through February 28, 1974 (3/29/74)

Why Do Disabled People Want to Work?

SIMON OLSHANSKY

". . . to seek to persuade a man that the misfortunes which he suffers are not misfortunes, does not console him for them, but is another misfortune in addition."—Calderon.

Generalizations regarding the meaning of work for the disabled are especially difficult to make since they represent so very diversified a population. Moreover, much of what we know about the disabled at work is superficial and based in large part on experiences with that small minority who become visible in the process of seeking help. While work is obviously important for most disabled persons, for some it may become a hazard to their health.

A General Statement

In our business society almost every adult is expected to work and to support himself by the sweat of his brow. Work defines one's status in one's eyes and in the eyes of others. *Who* you are depends on *what* you do. And *what* you do determines *where* and *how* you live and *where* and *how* you spend your leisure time. One's life expectancy and resistance to disease, as well as its treatment, are related to one's work and one's income.

The meaning of work has been changing during the last 50 years, and the attitudes of some of our young people reflect some of these changes. They want to work, but not hard. They value money, but value more the work they do. They want the goods of the world but place a limit on the price they will pay. They are not persuaded that more and more of everything means a better and happier life. *Making a living, they feel, somehow should be connected with making a life.*

Despite changes much remains the same. Hours of work for many continue to shorten while hours spent traveling to and from work continue to rise. And millions use their free time to hold a second job. Heavenly rewards are rejected for the fruits one can gather now, and since one lives once, one must "make it" while one can. Vacations, sick leave, and coffee breaks are important since they provide the relief from much of the tedium of work.

Essentially work is necessary if one is to function as an adult, to achieve financial independence, a sense of competence, and a feeling of self-respect. From his earliest moments man has sought independence and sought to engage in purposeful activities. Dependency, idleness, and indifference are unnatural, and their occurrence requires explanation because they are unnatural, Freud to the contrary notwithstanding. (*Civilization and its Discontents.* London: The Hogarth Press, Ltd., 1953, p. 34).

Further, I suspect that many persons accept with little or no thought life's necessities, and one of these necessities is work. And, generally, it is those who do not work who feel compelled to develop an ideology, as some beatniks do, or a rationalization, as some welfare recipients do, for legitimizing their avoidance of work. And some of those who rhapsodize most about the joys of retirement probably are scared to death of it and perhaps are persuading themselves that it won't be as bad as they fear.

Work is experienced differentially by members of the labor force. Professionals and managers tend to secure more work satisfactions and more money than nonprofessionals, who, while they value job security the most,

have the least. For many unskilled and semiskilled workers, the dissatisfactions of work are accepted as being less than the dissatisfactions of not working. How interesting it is that some people who could qualify for public welfare and who would be "better off" economically on it continue to work at jobs which offer so little security and such low wages.

However deadly work is for many, with its unending routine and its lack of challenge, it is in balance for most persons, probably less deadening and less destructive of one's self-respect than not working. That so many workers can tolerate day after day, year after year, such deadly jobs is both a happy and sad commentary on human stamina! One may note how tragic it is that so many must spend their years of life so uncreatively, just to endure.

An old German proverb notes that work makes life sweet. Perhaps not, but it does seem to make life more tolerable for most people.

Why Work?

Some professionals and lay persons have expressed surprise that so many people with disabilities work when they are eligible for various kinds of financial assistance, either through social security or public welfare, and when they might experience so many difficulties within the labor market. Despite the contradictory evidence, the traditional belief that few would exert themselves to work if not necessary for survival dies a slow death.

Basically, the disabled work for the same reasons as do the nondisabled—to function as adults, to gain financial independence, to develop feelings of competence, and to acquire self-respect.

But to the disabled the role and goals of work take on added or special meanings, since they often feel challenged and inadequate on the ground that they are less than adult. Because of the many uncertainties, anxieties, and feelings of differentness and apartness and because they often do need help, they begin to suffer feelings and fears of being childlike. And in some situations this feeling is reinforced when they are so treated. Being dependent on many occasions on someone, whether physician, social worker, or on any number of therapists, or on family members or friends, they are provoked to prove that they are not children and to prove that they are capable of functioning as adults. And how refreshing it is to them when they succeed!

Achievement of feelings of independence, competence, and self-respect, which are associated with adult behavior, becomes the measure of their adulthood. For this reason, while work according to Dubin (*The World of Work: Industrial Society and Human Relations.* Prentice-Hall, Englewood Cliffs, N.J. 1958) may be peripheral experience for some nondisabled persons, for the disabled it is more likely to become the central experience of their life. Without it they see themselves and are seen by others as more like children, living at the expense of others. Moreover, in their eyes and in the eyes of others *only their disabilities then become visible, and their disability becomes their identity.*

In addition, in a business society intolerant of weakness and committed to good health and good cheer and to "making it," work represents to the disabled the road to normality. It is expected of almost everyone, except the very young and very old and very sick. One exmental patient put it well when she said that each morning she boards the bus to work like everyone else and thus becomes as good as everyone else. Work provides one of the few occasions when the disabled can stand on equal ground with the nondisabled. The identity and identification as a worker places them along side of the nondisabled. Work gives them a sense of being someone, a way of denying and overcoming the weakness of disability. Work helps many feel that they are part of society and of a group, and helps them overcome their physical and psychological isolation, which may be a consequence of their disability.

Further, the spectre of boredom haunts many of the disabled, especially those with limited mobility, the mentally retarded, and many of those with a history of mental illness. Some of the mentally ill cannot even tolerate free weekends. Few of the disabled can provide ways of spending their time usefully or creatively. Thus, no matter how boring a paid job may be, it is generally less boring

than the idleness of unemployment.

Finally, work provides some needed opportunities for socializing, which is especially important for the disabled, particularly the large number without friends or friendly families. Social and recreational groups formed at work may become their major social links and their major source of leisure time activities. Besides, who does not need a change of scene? Think of spending each day confined to the same room or home setting! Work then provides the opportunities for socializing and the change of scene for many of the disabled who need help in securing both.

Because we have become a psychologically obsessed people, we have at times overlooked some conspicuously obvious reality factors. One such factor is the level of labor demand. Putting it another way, there are few motivating forces equal to job opportunity. And how much great talent must go undiscovered, wasted, because opportunities do not always become available? And the belief that man makes his own opportunity is a flattering half truth, reassuring to those who think they are self-made. The philosopher, Morris Cohen, has noted that the self-made man reflects little credit on his maker.

Work—Not Royal Road For All

While the value of work is central for most persons who are disabled, for some it may become a destructive experience. A few may so deplete themselves so as to shorten their lives; a few may subject themselves to great risks of injuries at work or in their travel to and from work; and a few, especially some exmental hospital patients, may have to be rehospitalized because they do not have sufficient energy to meet at one time the combined social, family, and work demands which daily confront them.

Some persons acquiring a disability at middle age may have to undergo so much humiliation because of job downgrading that it might be better for them not to work and to accept a dependent role. Some may tolerate the humiliation of idleness better than the humiliation of some lowly job of which they are capable and for which they would be accepted.

While work is therapeutic for most, it can for a few become antitherapeutic, a way of evading some problems they should face up to and deal with. As long as they work they can proclaim their normality and deny their problems.

For a few work may have no therapeutic effect. For example, some exmental hospital patients may work efficiently without any positive change in their emotional condition.

What is being protested here is the growing tendency to view work as the great panacea for all. If in the past its value was overlooked or looked down upon, the danger is that today its value may be exaggerated. It should be a matter of clinical judgment by the professional, together with the judgment of the client, to determine the value of work at different points of time.

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Civil Rights Victories for the Handicapped-II

FRANK LASKI

Part I of this article, in the May issue of THE RECORD, reviewed selected aspects of legal action on behalf of handicapped persons in the areas of education, treatment, and barrier-free environment. The impact of legal action on rehabilitation is explored below.

The legal developments noted in the previous installment have caused reverberations outside the courtroom and have influenced State and federal policymakers. Judicial action on right to education, and treatment has caught the attention of State legislators as evidenced by a recent resolution of the National Legislative Conference to develop model legislation relating to the needs of developmentally disabled persons, taking into account the role of institutions, education, and community programs.

More concrete examples are the hundreds of bills promoting education of the handicapped enacted into law by State legislatures during the last 3 years. Tennessee and Massachusetts have enacted comprehensive laws codifying many of the principles and rights enunciated in *PARC* and *Mills*. Implementation in North Dakota, Michigan, and Wisconsin is proceeding with an assist from potential or pending litigation.

In treatment, Massachusetts is implementing its completely revised mental health-mental retardation code, while at the same time under court order to provide habilitation to institutionalized mentally retarded. In Ohio and Florida, compre-

hensive codes incorporating a statutory right to treatment have been drafted and are before the legislature. An antipeonage statute has been enacted in Indiana.

At the federal level, the influence of the legal rights movement is reflected in both Congressional and Executive action. The Rehabilitation Act of 1973 is itself an important step in the movement toward the concept of habilitation and rehabilitation as an entitlement. The legislative history of the act shows a clear concern for client advocacy and client participation in rehabilitation plans. Title V is replete with new tools for advocates to assert rights to employment and access to transportation and buildings.

Amendments to the Civil Rights Act of 1964 to specifically protect handicapped persons from all types of discrimination has been urged by Congressional leaders, and a "Bill of Rights for the Retarded," incorporating the standards approach of *Wyatt*, has broad-based sponsorship in the U.S. Senate.

On the executive side, the President's concern for providing the handicapped ready access to the legal system and his directive to the Justice Department to take action to protect the rights of retarded persons has led to Justice Department participation as friend of the court in right to treatment cases and right to education. Most recently the Civil Rights Division filed suit on behalf of the United States challenging as unconstitutional the practices of an institution for the retarded in Maryland.

In addition, a number of HEW agencies are supporting advocacy efforts (including legal advocacy) on behalf of the handicapped without the ambivalence that has characterized administration support of advocacy on behalf of other disadvantaged groups.

The spread of legal action and the legislative and administrative reaction noted above have led some enthusiastic observers to speak of a rights revolution. Whether it is a revolution, quiet or otherwise, remains to be seen. Yet this much is certain, the decisions to date even in their most narrow construction are sufficient to bring about substantial changes in the State-Federal rehabilitation program. If unanticipated, these changes can cause dislocations and some turmoil within the system without much benefit to handicapped persons. If planned for, however, the changes generated by legal action could present opportunities for program advances in rehabilitation akin to those achieved in the past through federal legislation.

Rehabilitation planners should consider the programatic implications of right to education and right to treatment suits.

Public schools have consistently been an important referral source and focus of cooperative programing for VR agencies. In fiscal year 1969, cooperative education-vocational rehabilitation programs served over 100,000 persons. The majority of those served are mentally retarded; however, coverage extends to the mentally ill, persons with speech and hearing impairments, blind persons, and other physically handicapped of junior high and high school age. As legal action continues to effectively limit and possibly halt school exclusion practices, the public school pipeline to VR will change both in kind and numbers of persons served.

The cooperative programs focus on students of high school age, precisely the groups that are hardest hit by exclusion policies and practices. For example, the 1970 census of children not in any school in the United States shows that of the nearly 2.5 million children, ages 6 to 17 excluded, over one million are of the ages 15 to 17. Assuming that handicapped youth in school at age 15 or above are much more likely to reach vocational rehabilitation than those excluded from school before age 15, an end to school exclusion for this group may increase the pool of students for VR-school programs as much as 30 to 40 per cent.

In addition to greater numbers, other aspects of the cooperative school program caseload will change. Mandatory education for those in the upper teens and up to age 21, may divert or postpone some VR placements. In *Lebanks* v. *Spears*,[13] the first case to deal with the role of vocational rehabilitation in the context of right to education, the decree prohibits the placement of children under 16 in vocational rehabilitation programs. Thus, one hypothesis that merits investigation is that right to education will produce an increased number of older, more severely disabled, more educationally experi-

enced rehabilitation clients for VR-school programs.

Caseload characteristics are not the only programatic factors to be considered. Court orders pinpointing the education establishment as the public system responsible for the provision of free public programs of education and *training* of handicapped persons under 21 years of age will put VR-public school relationships on a different footing.

Courts have apparently accepted a definition of education which goes beyond the narrow concept of schooling. To wit: "Education is a *continuous process* of developing *life skills* needed for the effective coping with developmental tasks and demands as well as with environmental tasks and demands."[14] Since this formulation applies regardless of chronological age, extent of handicapping condition, or setting, it avoids and denies the relevancy of questions relating to boundaries between education and training.

If, as in *Lebanks*, vocational rehabilitation services are considered as alternatives to programs of education operated by the school system, then the procedural rights of notice, hearing, evaluation, plan, periodic review, which attached to regular class, special class or other placement, should apply equally to a vocational rehabilitation program.

In the same vein, rehabilitation agencies may be accountable directly to courts or indirectly through court appointed masters or education officials for closures of school-age cases not rehabilitated. They also may be

responsible for followup to insure an appropriate alternative education or training placement. Also, expanded VR responsibilities will likely emerge from consideration of the State's obligation to those over 21 who were denied education as children.

These new aspects of the VR-school relationship, deriving from judicial characterization of VR services as education, give rise to a series of complex issues of administration, organization, and financing of rehabilitation services for school-aged clients. For example, if VR services are provided to meet the State's legal obligation to provide education, should those services be financed from the same revenues as other educational services, giving VR some claim to the State-local education tax dollar? This question and related questions are beyond the scope of this paper. Suffice to say that they deserve serious exploration and that their resolution should not turn on whether or not a particular State VR agency is located within a State Department of Education.

The programatic implications of right to treatment also bear most heavily on VR cooperative programing. In this case, cooperative programs with State mental hospitals and State schools for the retarded will be affected. Minimal standards for treatment and habilitation include requirements for vocational rehabilitation services and make provision for minimum staff-resident ratios for rehabilitation counselors and other professionals.

Since the litigation on conditions

in State institutions is reinforcing a major trend in deinstitutionalization, additional rehabilitation resources will be required not only in the preparation and training of residents for discharge but also for continued counseling, services, and followup in the community.

In addition to accelerating the pace of rehabilitation-oriented activities in institutions for the mentally ill and mentally retarded, the right to treatment suits give rehabilitation agencies the opportunity to examine more closely how rehabilitation philosophy, programing, and techniques can contribute to overall institutional reform. For years rehabilitation programs of excellence have existed in institutions otherwise characterized by lack of programs and subcustodial environment. These vocational training and community placement projects, largely supported by RSA and NIMH, have amply demonstrated the value of rehabilitation in a residential setting. Yet, they have not had noticeable impact on the institution as a whole. In this light, the experience of post research and demonstration efforts, such as those undertaken at Elwyn Institute, should be reviewed and used as rehabilitation agencies work with State mental health-mental retardation agencies to implement the right to treatment.[15]

Just one thought about programatic implications of legal action on barrier-free environment. The direct connection between barriers and employment opportunity that the cases make is well known to rehabilitation counselors and much time and effort is devoted to overcoming the adverse impact of barriers on clients. Legal actions, such as *Metro* and *Friedman*, however, raise an additional possibility for vocational rehabilitation. It is the possibility that litigation or other legal challenge to barriers at a potential place of employment (or place necessary to enter in the course of employment) is an appropriate part of a client's rehabilitation plan.

Viewing the various legal actions as attacks on particular practices and examining direct program implications provides a limited perspective on the significance of the cases for rehabilitation and other as yet unaffected service systems. Perhaps the major future impact of litigation is grounded in the fact that all the decisions and decrees in one way or another accept, promote, and give public policy status to two theoretical constructs which have emerged recently to undergird new approaches to service delivery.

These constructs, the developmental model of disability and the principle of normalization, have been most widely used in the context of mental retardation and developmental disabilities but are applicable to all disabilities. Jacobus ten Broek set forth similar concepts of integration for physically handicapped persons,[16] and Richard Allen has given some thought to an across the board legal application of normalization to all handicapped persons.[17]

As outlined by Philip Roos, the developmental model views all retarded persons as capable of growth, learning, and development. Human development and behavior are products of interaction between the individual and his environment rather than attributes of a specific impairment. The model emphasizes the potential to alter development and incorporates positive actions to accomplish developmental goals. Consequently, it provides for the accountability of professionals and others for developmental failures brought about by lack of environmental conditions.[18] While the developmental model contemplates intervention to modify both behavior and environment, the normalization principle guides that intervention and requires that the handicapped person have an environment and life-style that is as close to normal as possible.[19] The normalization principle has been translated for use in educational services, residential services, transportation, social services, and, at one time, expressed in the SRS goal structure.

The developmental model and normalization principle provide a sound basis for the development of legal theories to protect rights of the handicapped. The developmental model of disability not only undercuts many of the assumptions behind existing statutes and common law restricting handicapped persons, but it provides a great part of the rationale for judicially mandated affirmative action to modify conditions detrimental to handicapped persons.

The normalization principle provides the courts with a useful gauge to develop standards of fairness and due process and assess accountability in relation to the extent to which practices isolate handicapped per-

sons. In this regard, the normalization principle links up with a congruent legal principle of right to least restrictive alternative. Generally stated, it holds that where governmental activity leads to regulation adversely affecting constitutionally protected activities or constitutionally preferred groups, there is an obligation to explore and employ alternatives which can accomplish governmental purposes through means least restrictive to personal liberties.

David Chambers has fully developed the legal thesis for least restrictive alternatives as applied to civil commitment of mentally ill and mentally retarded persons and has noted its limits and potentials in other settings.[20]

One may speculate, however, that in this area the law will not venture ahead of practice and that strength of the legal principle of least restrictive alternatives rests largely on the consistent articulation and application of the development model and normalization principle to all services for all handicapped persons, and the actual development of a range of alternatives for handicapped persons. Thus, it is timely, as legal action begins to impinge on the State-Federal rehabilitation system, to flesh out what these ethical and legal propositions mean in terms of rehabilitation and in the world of work with particular attention to sheltered work and economic security.

The extent to which legal developments tie into rehabilitation, programatically and conceptually, should not be surprizing. In mental retardation, for example, the connection is direct. As Gunnar Dybwad has explained, the knowledge base for the right to education movement rests largely on research findings of the late fifties regarding the actual work performance of retarded adults who had benefit of training and their capacity to live in the community.[21] It is the same knowledge base which supported the VR service development leading to a substantial increase in numbers of mentally retarded persons served and rehabilitated in the sixties.

Notwithstanding, a question remains as to the practical impact of legal advocacy on the operation of VR agencies. Will there be any real effect on the counselor, his supervisor, the service provider or the client? A doubting Thomas could dismiss predictions of any impact by pointing out rehabilitation's remarkable immunity to legal action. While State and local administrators of schools, public assistance programs, prisons, public housing programs, juvenile delinquency programs, and mental health facilities have all been subject to judicial orders requiring affirmative action, rehabilitation counselors and administrators have gone about their business without outside administrative or judicial intervention.

Legal action may be extrinsic to the rehabilitation process but certainly not to all rehabilitation clients, especially public assistance-vocational rehabilitation clients. State welfare agencies provide the contrast model to VR in terms of litigation. Beginning with *King* v. *Smith*,[22] which cracked the "man-in-the-house" rule in 1968, and continuing through the early 70's, the welfare system was subjected to a series of legal attacks by organized welfare consumers and poverty lawyers. Among the decisions which had the most impact on administration of public assistance was the 1970 Supreme Court decision in *Goldberg* v. *Kelly*[23] requiring an evidentiary hearing prior to termination of welfare benefits.

In the early 70's when, as a result of *Goldberg*, welfare fair hearings were yielding to a semblance of due process and contests over welfare benefits were commonplace, rehabilitation remained unaffected. At a time when the State-federal rehabilitation program was claiming over one million clients served annually, less than 500 clients per year requested formal administrative review of counselor action and an average of 41 clients annually requested fair hearings on their cases. For fiscal years 1970-1972, 25 of 52 general agencies and 20 of 24 agencies for the blind reported no experience with fair hearings.[24]

Why? One response is that rehabilitation clients, whether they are successfully rehabilitated or not, and regardless of the extent of services received, are satisfied with service they do receive and have a positive relationship with their counselors and the program. There is some evidence that this may be the case in rehabilitation more often than it is in other service systems; however, it would clearly be misleading to use lack of

administrative appeal or fair hearing experience as an index of client satisfaction.

Failure to use fair hearings or appeal mechanisms may stem from the client's lack of awareness of procedural rights, his perception of the counselor as an absolute decision-maker and the client's dependency status. The importance of establishing a right of the client not to be dependent on agency whim has been elaborated upon in the welfare context by Edward Sparer.[25] In the sense he uses the term dependency, the rehabilitation applicant or client is likely to be more dependent than the welfare recipient, but for very different reasons. The extent of dependency turns on counselor and client perceptions and can be gauged by considering the following questions: 1) Does an applicant, clearly eligible for VR services, receive them as a legal right rather than as a matter of agency discretion? 2) Are eligibility criteria communicated so as to be susceptible to determination by objective standards? 3) Is there an effective mechanism to exercise appeal action on services before services are terminated?

In terms of past VR practice, it is unclear how the above questions would be answered. However, if practice begins to conform to the mandate of The Rehabilitation Act of 1973, the answers from both clients and counselors will be increasingly in the affirmative.

The Rehabilitation Act of 1973 provides for the mechanism most essential to due process in any service delivery setting—the individualized plan. The concept of a plan is embodied in Section 102 of P.L. 93-112 which requires that the counselor and client jointly develop an individualized, written rehabilitation program that includes the terms, conditions, rights, and remedies under which services will be provided.

Essential elements of the written program are long-range and intermediate rehabilitation goals, statement of specific services to be provided, timelines for provision of services, objective criteria and processes for program evaluation, and notice of availability of client assistance project. The law also sets forth requirements for annual review and modification of the client program and specifies procedural guidelines for terminating service and a strict standard for finding ineligibility for service.

It would be a mistake to discount the significance of Section 102 to the State-Federal rehabilitation program or to consider it merely a restatement of former regulations governing the vocational rehabilitation plan for the individual. Whereas the former regulations promoted agency discretion at the expense of client dependency, Section 102 imposes a new degree of accountability for counselor action and agency decisions. In fact, Section 102 goes a long way, if not all the way, to establishing a contractual basis for the provision of rehabilitation services.

The approach of Section 102 and the introduction of formal due process safeguards raise many complex issues not present in simpler settings such as welfare. Some professionals may question the imposition of any client-centered accountability process just as some educators have raised doubts about due process hearings for class placement, and some physicians have fought Professional Standards Review Organizations. There is no gainsaying that there are questions the Rehabilitation Act does not resolve. The scope of rehabilitation services, and the range of clients and client needs preclude the development of a single statutory formula which will preserve the positive aspects of the counselor-client relationship and at the same time provide a structure which will safeguard client rights. Rehabilitation counselors and clients should not be left at large for long as to the operational requirements of the Act. Most questions can be dealt with in regulations and guidelines or on a case by case basis through appropriate administrative procedures. Forward planning at the State and federal levels should leave only a few questions for the courts.

This paper has not dealt directly with the questions of whether handicapped persons have a right to rehabilitation services and whether such a right is enforceable against State rehabilitation agencies. Hopefully, the reader in reviewing the legal developments in treatment, education, and barriers, outlined in Part I of this article, will see that these are, in many respects, the wrong questions. They are premature. They ask too much but, at the same time, frame the issues too narrowly.

Any serious consideration of a right to rehabilitation must not be limited to the context of handicapped persons versus State rehabilitation agencies. Rather it must address issues of public responsibility to handicapped persons for the equitable provision of the major components of rehabilitation, such as medical care, higher education, vocational training, and must address itself to public and private obligations to provide handicapped persons with decent employment opportunities.

While the ethical theory, legal doctrine, and the constitutional and statutory basis for a right to rehabilitation could be developed, it is certain that neither agencies nor courts will deal with the issue comprehensively. More likely, the rights of handicapped persons relating to rehabilitation will evolve from a series of contests and determinations about discrete and seemingly unrelated issues. The evolutionary path of the rehabilitation rights development is a matter of conjecture but at least three avenues are open:

■ *Definition of existing statutory rights.* It is evident, at least in this writer's view, that handicapped persons walk into rehabilitation agencies and other public human service agencies with a bundle of rights, most guaranteed by federal law, which have been heretofore unrecognized and thus untested.

■ *Expansion of rights in other areas.* Something akin to a right to rehabilitation may emerge full blown from the convergence of right to education, right to treatment, and right to employment. Only time will tell.

■ *New statutory rights and equal protection.* The enactment of a statutory right to rehabilitation for a certain class of handicapped persons (*e.g.*, the industrially injured as recommended by the National Commission on Workmen's Compensation) may lead to a more generally applicable right to rehabilitation on equal protection grounds.

Other avenues will open up and develop as legal action unfolds. The role of rehabilitation professionals in this development is yet to be determined. At a minimum, rehabilitation officials and service providers must insure that their procedures guarantee due process and equal protection to all handicapped clients. Ideally, rehabilitation personnel will look beyond possible challenges to agency practices, ally themselves with handicapped persons seeking to assert their rights and, where appropriate, invoke legal processes on behalf of handicapped persons as a means of furthering sound public policy in rehabilitation.

Mr. Laski is a member of the Bar of Massachusetts. He is currently on the staff of the National Center for Law and the Handicapped.

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Publications and Films

The Editors of the SOCIAL AND REHABILITATION RECORD regularly receive notification of the release of new publications and films of interest to readers.

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Camping Therapy. Thomas Power Lowry, M.D., F.A.P.A., editor. Charles C Thomas, 301-327 East Lawrence Ave., Springfield, Ill. 62703. 138 pages. $7.75.

In this book, Dr. Lowry and 17 other contributors discuss the uses of camping therapy in psychiatry and rehabilitation.

The articles include a historical-philosophical overview; discussions on camping therapy applied in cases of psychosis, juvenile delinquency, childhood neuroses, mental retardation, and day care status; and a perspective essay on man's spiritual relationship with nature. Frustrations as well as triumphs are discussed, and pitfalls to be avoided are listed along with guides to success. Suggestions for materials and resources, plus hints for establishing and implementing an economical camping therapy program conclude the volume.

The Group As Agent of Change. Alfred Jacobs, Ph.D., and Wilford Spradlin, M.D., editors. Behavioral publications, 72 Fifth Ave., New York, N.Y. 10011. 463 pages. $19.95 hardbound and $9.95 paperbound.

This comprehensive anthology presents the most recent efforts by leading theoreticians and practitioners to utilize group methods of intervention. The book shows how groups can be used for the facilitation of personal growth, the treatment of mental and social disorders, and for the socioemotional education and enrichment of the human state. The authors show how "group phenomena technology" can be used in a remarkable variety of settings, from kindergarten and family to the mental hospital ward and the community.

An introductory section generates an historical and cultural context for the use of group methods of intervention. Other chapters provide descriptions of various programs and approaches, focus on theory and concepts, and review contemporary literature about the determining variables in group intervention.

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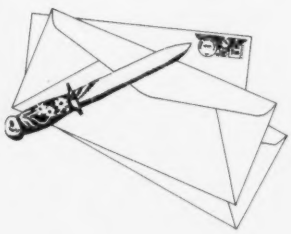

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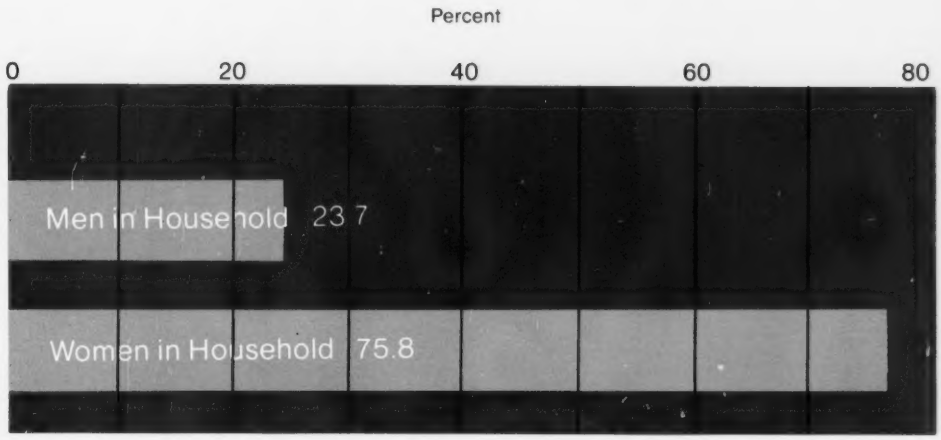

In January 1973, less than one-fourth of AFDC families were headed by a man, and only about half of the male heads were natural or adoptive fathers of the children receiving AFDC. Over three-fourths of the AFDC families were headed by a woman, and most of these women were the natural or adoptive mothers of the AFDC children. In March 1973, about 88 percent of all families in the U.S. were headed by a man (current Population Reports, Series P-20, No. 251, June 1973).

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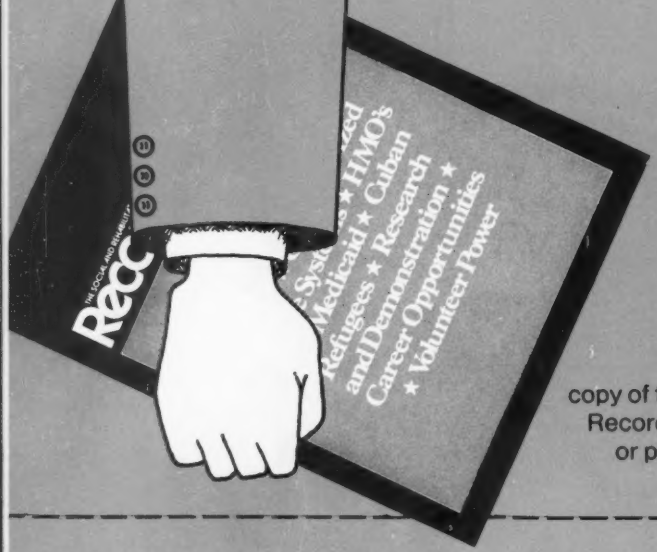

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